DOCUMENT RESUME

ED 115 067 EC 080 660

AUTHOR	Morrison, Jan; Wood, J. Marcus
TITLE	To Find the Invisible Child: A Report on Casefinding.
INSTITUTION	Ohio State Univ., Columbus. Herschel W. Nisonger Center.
SPONS AGENCY	Bureau of Education for the Handicapped (DHEW/OE), Washington, D.C.
PUB DATE	[74]
GRANT	OEG-0-73-5583
NOTE	43p.
EDRS PRICE	MF-$0.76 HC-$1.95 Plus Postage
DESCRIPTORS	Exceptional Child Education; Handicapped Children; *Identification; Parent Counseling; *Preschool Education; Professional Occupations; *Program Descriptions
IDENTIFIERS	Casefinding Coordinator; Developmental Disabilities; *Developmentally Delayed Infant Education Project

ABSTRACT

Presented are some casefinding approaches used in the Developmentally Delayed Infant Education Project (Ohio). Brief sections include information on the Project's objectives and limits; the responsibilities, desired skills and competencies, and desired traits and attributes of casefinding coordinators; identification approaches (such as contacting social service agencies and medical facilities, reaching parents through the media, and mass screening); ways to handle initial contacts and testing in the home; approaches to handle parents of children accepted or denied acceptance into the program; and common parental concerns (such as cause of the child's delay). Among information appendixed are criteria for infant selection, general admission procedures, and guidelines for follow-up. (SB)

****
* Documents acquired by ERIC include many informal unpublished *
* materials not available from other sources. ERIC makes every effort *
* to obtain the best copy available. Nevertheless, items of marginal *
* reproducibility are often encountered and this affects the quality *
* of the microfiche and hardcopy reproductions ERIC makes available *
* via the ERIC Document Reproduction Service (EDRS). EDRS is not *
* responsible for the quality of the original document. Reproductions *
* supplied by EDRS are the best that can be made from the original. *
****

ED115067

U.S. DEPARTMENT OF HEALTH,
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

A Report on Casefinding

Jan Morrison, A.C.S.W.

with
J. Marcus Wood

TO FIND THE INVISIBLE CHILD

EC 080 660

AN INTRODUCTION

No child is invisible. He (or she) is a durable being, a whirlwind of activity—dr[illegible] pushing, struggling toward maturity as he grows and develops. The wond[illegible] of watching a child grow is beholding his tenacious grip on life no matter wh[illegible] his circumstances might be.

Every activity marks affirmation of his life, individuality, and the right to pursue, unhindered, his potential.

A child may not realize his potential if for one reason or another he is delayed in some area of development. He may have no serious physical or neurological handicap. The delay may be hardly noticeable to his parents. Yet if the delay is not discovered, the child may not be able to realize his individual potential.

The child with developmental delay has largely gone unnoticed because this handicap may be an almost invisible one.

To Find the Invisible Child reports the activities and approaches of one project in its effort to locate children w[illegible] developmental delay.

The emphasis of this booklet is o[illegible]e casefinding efforts of the Developmentally Delayed Infant Educa[illegible] Project of the Nisonger Center for Mental Retardation and Developmental Disabilities located at the Ohio State University.

The project, now in its outreach phase, has provided a stimulation program for young children between the ages of six months and thirty-six months who are developmentally delayed.

This booklet does not pretend to contain all-inclusive knowledge concerning casefinding. It attempts to relate, in practical terms, some approaches for finding children with developmental delay and gaining the trust and cooperation of their parents.

There are no easy paths to casefinding—especially when the children involved often have no visible or obvious handicaps. It is hoped that this booklet will help and give perspective to those currently involved with casefinding efforts directed toward young children with developmental delay or for those who may be considering beginning such activities.

CONTENTS

Who is the Invisible Child?	6
Wanted: A Casefinding Coordinator	8
Wanted: Young Children with Developmental Delay	10
Handling Referrals	15
Denial, Acceptance, and Entry	18
Handling Parent Concerns	21
Appendix	25

WHO IS THE INVISIBLE CHILD?

Consider for a moment searching for and finding a child, *an invisible child*, who:

— according to the 1970 census may be part of the 10% of the total new-born population who will eventually suffer developmental delay

— is under two years of age

— has no known or recognizable neurological or physical handicaps

— is functioning cognitively below the normal range for this age group

— lacks in his environment stimulating activities and experiences needed to promote normal growth and development

Then consider that if the child's delay remains unidentified and a program of early intervention and stimulation is not begun, the child may:

— continue to lag further and further behind his peers in growth and development

— be labelled as a "slow learner" or "retarded" upon reaching kindergarten or the first grade of school

— may never have the opportunity to realize his potential for normal functioning

In short, the *Invisible* child may become all too *Visible*—when it's too late.

THE INFANT PROJECT

The Developmentally Delayed Infant Education Project, or the Infant Project, was designed to meet the needs of these *invisible* children by:

— identifying their delay

— involving them in a stimulation program at as early an age as possible

— working with their parents

The program primarily worked with the mildly delayed child with no gross neurological or physical handicaps. A smaller number of children with more severe delays were also included in the program.

Normally functioning children were also included in the classroom. These children provided models for the delayed children to imitate, since much of what a child learns is through the imitation of others.

LIMITS

The Project sought to have a cross-section of children along economic, racial, and sexual lines.

The Project provided transportation within a geographically defined area. This area was determined by the practical aspects of how many children could be picked up by one car and one driver within a certain time period. The primary catchment area was generally populated by lower-income families. Children outside this area could participate in the program if transportation was provided.

But before the program could begin, children had to be found, parental cooperation gained, and relationships with possible referral sources developed. In short, a casefinding effort had to be begun.

Responsibilities

Initiates, establishes, and maintains relationships with community agencies that are potential sources of referral of children to the Infant Project

Establishes first contacts and working relationships with families referred

Coordinates all project efforts to locate young children with developmental delay

Desired Skills and Competencies

Must have knowledge of the growth and development of young children

Must be able to inform and educate community service and medical personnel on developmental delay in young children

Must have working knowledge of developmental tests and testing procedures for young children

Must be prepared to deal with possible anxiety and fears of parents of young children with developmental delay

Must have an exhaustive knowledge of community resources and materials helpful to young children with developmental delay

Desired Traits and Attributes

Must be flexible, persistent, adaptable, honest, self-confident, understanding, practical

Must be able to work with people from every type of background imaginable

Must be prepared to be an educator, coordinator, counselor, publicist, salesperson, advocate, community developer, child development specialist

Must not be afraid of hard work and long hours

Must be motivated by a desire to locate and help children with developmental delay and their families

The casefinding role in the Infant Project required all of these attributes and

sometimes much more.

A casefinder in a program like the Infant Project must be prepared to analyze the community and know its people and resources. She (or he) must explore every approach to finding young children with developmental delay. The job demands much know-how and *INGENUITY*.

Before going further, think for a moment of how *you* might go about finding young children with developmental delay in your community . . . Then compare your ideas and approaches with those of the Infant Project described in the next section.

The Infant Project found through hard experience that there is no *one* correct way to identify children with developmental delay. The Infant Project used in its casefinding efforts several different approaches.

Regardless of the approach, the keys to success were *Information* and *Persistence* and *Patience*.

Information:	about the program, its operation, and developmental delay—this information had to be adapted to meet the needs of a variety of different persons such as parents, agency directors and staffs, and physicians
Patience and Persistence:	repeated contacts and explanations were a casefinding fact of life—contacts and explanations *ad infinitum* were not too high a price to pay in locating the children of concern

APPROACHES TO IDENTIFYING CHILDREN WITH DEVELOPMENT DELAY

Contact Social Service Agencies and Medical Facilities

They proved to be valuable referral resources through their contacts with parents and children.

The approach to contacting these agencies began by calling the director by phone, giving information about the project, and requesting a time to present project information to the staff. Often the time suggested was a weekly staff meeting. This time usually insured a good opportunity to contact a maximum number of staff members.

The presentation usually lasted about half an hour and included:

1. Introduction by director or supervisor of facility of the Infant Project representative.

2. Explanation of presentation by the Infant Project representative.
3. Slide-tape presentation about the Infant Project (a basic information-giving presentation developed by the Infant Project and lasting 10-12 minutes).
4. Distribution of Infant Project literature to all staff present.
   A. Pamphlet describing the Infant Project
   B. Criteria for Selection sheet (see appendix)
   C. Casefinding Procedure sheet (see appendix)
5. Discussion about the Infant Project, criteria for selection, and referral system with the staff present.

This approach had the advantage of helping develop personal contacts and working relationships as well as clarifying points of information by group discussion.

However, there were disadvantages to this approach. So much information given out at one time may not be correctly remembered. Further contact to explain the Project and its aims was often necessary.

The establishment of working relationships with these agencies was often hampered by the high mobility of people in community service facilities. This made continuity of service to families and children difficult to maintain. This, however, was a reality and had to be adjusted to.

One way the casefinder avoided these disadvantages was by making program presentations to service agency staff every six months, if at all possible. This assured the best interests of the Infant Project would not be forgotten by these links in the referral system.

The following are examples of service agencies which were successfully contacted using this approach:

1. neighborhood settlement houses
2. county and state welfare agencies
3. well-baby clinics
4. public and community health nurses
5. religious service agencies and churches
6. social service agencies
7. day-care centers
8. community mental health agencies
9. schools
10. hospital clinics
11. children's services boards

Informing and Involving Pediatricians

This second approach aimed at pediatricians as an important referral source. Few referrals had come from pediatricians though it was known pediatricians see young children with suspected developmental delay.

Information was sent out to fifty-six registered M.D.'s in the primary casefinding area. Sent to each was:

1. a letter describing the program
2. program brochure
3. criteria for selection sheet
4. casefinding procedure sheet

The Project followed this first contact with a second set of contacts which included:

1. conducting a second mailing
2. following the mailing with direct phone calls to answer questions raised by the letter
3. having a social get-together for pediatricians and Infant Project staff

Reaching Parents through the Media

Activities in this casefinding approach included:

1. articles about the program and about developmental delay published in city, neighborhood, and University papers
2. the showing on local television of a one-minute public service announcement concerning developmental delay produced jointly with another agency interested in locating children with developmental disabilities

Mass Screening

Mass screenings in the community provided an avenue for directly reaching parents and children.

In mass screenings, testing facilities were set up in the community where parents could bring their children for free developmental testing. The Denver Developmental Screening Test was used in the mass screening. It was followed on a later date by testing with the Bayley Scales of Infant Development if the Denver results indicated a child was delayed.

The best publicity for the mass screening was found to be mass distribution of one-page flyers with locations, times, and dates of the mass screening. These were distributed in grocery stores, day-care centers, laundromats, churches, and community centers.

Two mass screenings were conducted with the second concentrating on lower-income areas. In these mass screenings almost a hundred children were tested. A third mass screening was held in April, 1974. This screening was conducted to identify more children for the Project's classroom and to offer a community service by providing free developmental assessment for children six months to two years of age.

The planning timetable for the third mass screening was as follows:

Activity	Time from Screening Date
1. Tentative plan and time line for mass screening submitted for agency administration approval and recommendations.	8 weeks before
2. List of community social service agencies, churches, schools, and day-care centers compiled and letters sent inviting personnel to a meeting with Infant Project staff about mass screening plans	6 weeks before
3. Begin to recruit people to do testing at mass screening sites	6 weeks before
4. Follow-up phone calls by Infant Project staff to community people to whom letters were sent —List of people coming to meeting compiled —Partial list of facilities for test sites and people to distribute flyers compiled	5 weeks before
5. Meeting of community people —Complete list of facilities available for testing sites —Complete list of people and places to distribute flyers	4 weeks before
6. Choose testing sites and have flyers printed	3-4 weeks before
7. Distribute flyers to community facilities to distribute to their contacts	2-3 weeks before
8. Finalize list of testers and their screening sites and inform them	2 weeks before
9. Post flyers in community grocery stores, laundromats, bars	1-2 weeks before
10. Visit chosen test sites to preview arrangements for mass screening personnel	1-2 weeks before
11. Tie up any loose ends and get material ready for each screening site, i.e., test kits and score sheets	1 week before
12. Mass Screening	
13. Review test data and arrange re-test appointments where necessary	1-2 weeks after

14. Send letters to parents of normally functioning children	2 weeks after
15. Complete re-testing of children with signs of delay and determination of referral sources for them	2-6 weeks after
16. Complete report and data compilation of mass screening	6-8 weeks after
17. Send copies of report to community facilities contacted originally and all other people involved in mass screening	8 weeks after

The third mass screening emphasized the involvement of people from community facilities. This involvement both increased the Project's range of community services and expanded its referral system.

Many service centers offered help by aiding in screening, distributing the flyers, and volunteering the use of their facilities as screening sites.

The interest of the community people in this effort and the relationships formed as a result of cooperation with the community greatly helped the Infant Project better serve the community. In turn, the community helped the Project to continue its services.

A NOTE FOR READERS

All the casefinding efforts described in this section attempted to reach all segments of the community. Should you choose to follow any or all of them in your casefinding efforts, bear in mind the following:

1. Developmental Delay in young children may not excite immediate interest in the people you contact—or, do not expect large returns at first.
2. Present succinct information which appeals to the specific group you wish to address.
3. Be persistent. Repeated contacts and exposure to the essential information is a necessity if a good referral system is to be put together.
4. Casefinding efforts must allow for a great deal of flexibility and ingenuity. The size and nature of the professional community and community-at-large provide the best guides for employing any casefinding effort.

All casefinding efforts are designed to lead to *Referral*.
Generally, referrals were made to the Infant Project in one of three ways:

1. the parents of a child called;
2. a staff member of an agency working with a family contacted the Project; or
3. Project staff members saw a child and parents at a mass screening or well-baby clinic where the staff offered free testing for developmental assessment.

THE INITIAL CONTACT

The initial contact established the appropriateness of the referred child for the Infant Project.

The *Initial Referral Form* (see appendix) answered such questions as the child's age and where the family lived. Further discussion centered around the child's degree of disability and the results of other tests the child might have had.

Within ten minutes of discussion with the referral source, it was usually possible to determine if the Infant Project could be helpful to a child, or whether another source would be more appropriate.

Depending on the determination of the child's needs, the initial contact ended in one of three ways:

1. an appointment to test the child;
2. a referral to another source of help;
3. to have further contact with the referral source if the source did not have all the information necessary to make a decision about a testing appointment for the child or referral to another source.

Many times the casefinder had to inform parents or agency workers about the specifics of the Infant Project during the initial contact.

While the casefinder took information about the child and family, she often acquainted the referral source with the program. This often proved tiring time after time. However, the more graciously this situation was handled, the more comfortable the atmosphere that was established.

PARENTS AND THE INITIAL CONTACT

The initial contact with the parent needed to be handled with concern, kindness, and understanding.

This contact was often the parents' first try at obtaining help for a child. This effort often came at the end of long thinking and soul searching to adjust to and accept the child's disability.

The reception to the parents' effort by the casefinder was crucial. The parent (usually a mother, though a father sometimes called)

1. needed to be applauded for this effort in seeking help for her child;
2. needed to go away with something concrete such as an appointment for testing by the Infant Project or referral to another source;
3. needed assurance that that resource could help.

A follow-up call by the casefinder after a period of time to the referral source suggested insured follow-through on the referral. Parents could also be assured that others wanted to help them and their children, too.

Many times the parents wanted to consult their pediatrician or other medical personnel they were in contact with before involving their child in the Infant Project.

In these instances, the further contact was usually left to the referring source. If a long time period elapsed, the casefinder initiated the second contact in an effort not to lose a child who needed help.

TESTING IN THE HOME

When, as a result of the initial contact with the referral source, a decision was made to test the child, the casefinder arranged to visit the family's home.

This gave the casefinder an opportunity to talk with parents and observe the home setting as well as test the child.

If there was prior indication the child was behind in his development, the *Bayley Scales of Infant Development* was administered. If no delay was indicated upon referral, the *Denver Developmental Screening Test* or the *Bayley* was given.

To obtain more specific information about a child's functioning level, the Infant Project tended to initially employ the *Bayley*.

In a program having a heavier referral load of potentially normal children, the *Denver* should be employed initially and the *Bayley* used as a follow-up for suspected delay.

The visit was made to the home, rather than have the child tested elsewhere, for several reasons.

Although many children are very cooperative, generally testing children between six months and two years is not as easy as one might think. Young children often react negatively to new situations and new people. In addition, they

have a difficult time sitting still for long. Most of the time, the familiar surroundings of the home make the child more comfortable with the test situation, the tester, and the test items.

Both the parent(s) and the child are at ease in familiar surroundings. Children tend to get higher scores when tested at home than if they are tested in an unfamiliar setting. It is important not to slant the test results in favor of the child; it is also important to give the child the advantage of performing as well on the test as he can.

While testing in the home setting, the casefinder had an opportunity to observe the child's surroundings that contribute to his growth and development. The test situation was used to do this. Such things as how the child and family members relate, how many and what kinds of toys a child has, and how he plays with them are all important to observe.

When appropriate, the casefinder made suggestions to the parent while administering the test. Helpful activities and toys were often discussed.

It was helpful to have both parents present on this first home visit. Each parent could then make his own contribution to the casefinder's understanding of the child's problem.

After testing was completed, the casefinder made sure the parent understood the Infant Project and its requirements. The casefinder then informed the parents that test results and a decision regarding programming for their child would be available within a week.

The test results were the final deciding factor in determining a child's appropriateness for the Infant Project along with his age and how he was transported to the classroom.

The test results, and home visit observations were later related to the rest of the Project staff who, in turn, made the final decision about the child's entrance, or referral to another program (See form, *Criteria for Infant Selection*, appendix).

The second contact with parents of a referred child usually let them know whether the child was accepted into the Infant Project or referred to another resource.

In either case, parents were told the reasons for the decision. Their questions and comments were invited to make sure there was no misunderstanding about the decision.

In situations where the child was denied entrance to the Infant Project:

1. he was functioning at a normal level for his age;
2. or the child was too delayed for the Infant Project.

In the first case the test results generally assured parents their child was doing well. In some instances, the parents requested assistance in maintaining the level of development of their child.

What could be suggested depended upon available community resources. The Infant Project suggested:

1. parent training groups;
2. a home-based activity program for normally functioning young children;
3. books about child development and learning activities for young children.

One of the *more difficult problems* to handle with parents occurred when a child was found to be too delayed for the Infant Project.

Usually if a child was significantly far behind in his development, the parent was aware that the child had a problem before testing. However, the parents were often not prepared to accept how serious the child's problem was.

Their fears and concerns had already been stimulated by the awareness that the child potentially had a problem. The reality of the serious degree of delay and rejection by a program because of this delay only heightened these existing fears and concerns.

In many of these instances, the Infant Project was the first contact parents had concerning their child. *The casefinder helped such parents not become overwhelmed by their problems and think the worst of their situation.* This was done by *encouraging the parents to voice their concerns and questions, answering these as honestly as possible,* and *referring them to an appropriate community resource.*

While it was difficult to handle the feelings and questions of those parents of children whom the Infant Project could not accept, the job of involving parents and children within the Project was equally difficult at times.

The majority of parents with children accepted by the Project were eager for the opportunity for their child. Some parents were not quite as willing and enthusiastic although they could see the need for their child to be involved.

In acceptance cases, the most difficult situation was the parents who originally had no suspicion their child was delayed.

In such instances, the child was usually mildly delayed, the delay being so subtle that the untrained eye of the parent could not observe it. However, testing could define it.

The presentation of the *test results to the unsuspecting parents was best done on a home visit, if possible, rather by telephone.* The parents often registered shock, surprise, and disbelief and asked many questions in their efforts to gain understanding of the child's delay. They often wondered why they hadn't seen the problem themselves. Such parents usually accept the evidence identifying the delay, but struggle frequently with feelings of guilt—blaming themselves for their child's delay.

Often the casefinder encounters parents who understand their child needs help, but still cannot fully accept their child's delay and need for help.

One can only speculate why such parents have difficulty in accepting the specifics.

These parents are torn by a desire to do what is right for their child and a nagging fear their suspicions will be verified.

The casefinder eased their struggle by helping them talk out their concerns and feelings before deciding to enter their child in the Project.

The other area of difficulty encountered in a child who has been accepted by the Project were parents who had a hard time entrusting their child to someone else's care.

These parents typically either had their children removed from their home at one time by a children's services organization or were threatened with their removal. The scars of this experience left the parents nervous about other people caring for their children. They were supicious of such programs as the Infant Project. Parents could not be blamed for feeling protective toward their children. The casefinder had to gain the parents' confidence in these cases. Often several home visits and much patience and understanding was demanded of the casefinder.

But with few exceptions this draining, yet delicate affair in basic human sensitivities resulted in gaining the parents' trust.

This entire issue of dealing with parental concerns and gaining their cooperation will be examined in greater detail in the next section of this booklet.

ENTRY INTO THE PROGRAM

After the child had been accepted into the program and the parents agreed to their child's entry, the casefinder scheduled another home visit during which:

- Parents were introduced to their assigned family worker (an Infant staff person)
- Plans were finalized for the child's entry
- Details of the parents' involvement in the program were discussed
- All aspects of the program were gone over again
- A commitment was asked of the parents to:
  - attend one classroom session per week
  - arrange weekly home visits with the family worker
  - attend weekly parent group meetings
- Transportation plans were made and necessary forms signed (See appendix)

THE FIRST DAYS

On the child's first day in the program, every effort was made to make both mother and child comfortable with the situation.

The mother was asked to attend the first two days (or more if the child was under a year old or was having obvious adjustment and separation problems) to lessen her anxieties over this new situation. If the mother and child lived in the catchment area, the casefinder often picked them up herself.

Upon arrival, the Infant Project staff was introduced to the mother. She was then familiarized with the classroom's operation, materials, and equipment.

Once the child entered the Infant Project, the casefinder's active involvement with a family ceased, and was assumed by the family worker. In situations where the assignment of the family worker was delayed, the casefinder continued involvement with a new family until a family worker was assigned.

As a final contact with the family, the casefinder sent an evaluation form of the intake process to each new family a week after their child entered the program.

Through these evaluations the casefinder often received helpful criticisms which helped improve the intake process.

HANDLING PARENT CONCERNS

From the time of the initial contact up until the child's entry into the Infant Project, the casefinder had to deal with parent concerns.

The casefinder had to be sensitive to the different family situations she encountered. Every situation seemed to demand a different approach.

Some initial approaches the Project found useful were:

- Listening to parents' concerns and questions and dealing with their feelings about their child's delay, letting them know someone cares about their problems and wants to help
- Using another person who is known and trusted by the family such as a nurse or community service worker to accompany the casefinder if parents are suspicious or hesitant about involving their child in the program
- Arranging a visit to the classroom for parents, letting them observe it in operation and meeting the people who will have responsibility for the well-being of their child.
- Repeating visits to the family on an informal basis to help parents voice their concerns and deal with their own feelings, extra visits establish trust and a sound working relationship.

The following are the most common parental concerns encountered by the Infant Project and how the Project dealt with these concerns:

1. *Many mothers felt their child was too young, especially if he was under one year of age, to leave the home setting and be in another setting with other adults and children for two and a half hours a day, five days a week.*

To *approach this concern* was to first assure the mother that in most instances, the involvement of a young child in such a program was not harmful to the child; that caution was taken in not overstimulating a child of any age; and that the overall experience generally promoted and helped the child's development.

If it seemed appropriate, the casefinder also discussed with the mother why

she hesitated to have the child leave home each day, whether she would feel lonely, or unneeded, and ways in which she could benefit from the extra time she would have while the child was in the classroom.

The importance of her being in class with her child was also stressed as well as contributions she could make to the Project (like making toys).

2. *Parents wanted to know how their child would benefit from the program; whether a delayed child will leave functioning normally; and if the Project could guarantee a child's success.*

The parents were informed of the individualized activity program which would be planned for their child at his developmental level in various areas. They were told of the supervision of the child's program by a teacher specially trained in working with children with developmental delay and the periodic evaluation of the child's progress in the program.

The Infant Project could not guarantee their child's overcoming a delay by participating in the program, but evidence from children previously in the Infant Project and studies of similar projects supported the fact that such programs did benefit a child's development.

3. *Parents wanted to know the cause of the child's delay and if the delay was permanent or correctable.*

These were generally questions the casefinder could not answer. Usually, the parents were assured that efforts would be made to determine the answers while the child was in the Project.

Parents were also made to understand that not all their questions were answerable. They were encouraged to concentrate on helping their child reach his potential rather than concentrate on the origin of his problems.

4. *Parents wanted to know if in any way they could have contributed to their child's delay.*

Due to her limited observation of the family setting, the casefinder could not directly give the parents answers.

The casefinder did point out experiences and activities helpful to a child's development.

Again the emphasis was on working on the child's problem rather than dwelling on the cause of the problems.

5. *Parents asked if a normally functioning child (normal model) would receive the same program benefits as the delayed child.*

This question was asked by every parent whose child was a potential normal model for the Infant Project. The parents were generally concerned that their child might regress in his development as he played with children who were delayed. The parents were assured that the normal models in the classroom would get the same individualized program of activities appropriate to their developmental level as did the delayed children. They were told other normal models in this program, and in other programs, had not regressed. In fact most

had been boosted in their own development through involvement in such a program.

6. *Parents were concerned they could not meet expectations for their own involvement in the program.*

In responding, the casefinder often assisted parents in sorting out their time commitments, and realistically assessing how much involvement they could expect in the project. Since each family had different time problems, the casefinder had to be attuned to each new family in helping them find a time in their schedules for family visits, classroom visits, and parent group meetings each week.

The project did let parents know that their participation was expected and that this was a serious commitment.

7. *Parents wanted to know if they would be informed of what was happening in the program, how the child was progressing.*

Although parents recognized the benefits for their child, it was not an easy thing for them to entrust their child's care to other adults.

They wanted to make sure that avenues were open for knowing what was happening to their child. This, of course, is a right of any parent. The parents were encouraged to ask such questions and to maintain an interest in their child's development.

This concern was used to encourage parent participation; parents were invited to talk with the teachers about their child's progress and current activities.

8. *Parents often inquired about the backgrounds of the staff members.*

Again, the answers to this question helped assure parents that they were making the right decision for their child. The casefinder had information about the staff members so she could answer the parents' questions satisfactorily. It is a parent's right to have this information if requested. It proved helpful to have a list of the staff members, their positions, and work phone numbers to give interested parents.

9. *Parents asked if there were alternatives to the Infant Project.*

Parents had a right to know all the program choices available before deciding on one for themselves and their child. For the parents of a child who met the Infant Project criteria, this was a particularly crucial question.

The casefinder had to be as familiar with alternative forms of programming in the community as possible, and to share this information with parents.

If an alternative was chosen, the casefinder did everything possible to help the parent pursue this.

A FINAL POINT

These concerns were among the most common expressed by parents. There are more, of course, but these revealed much of the parents' inner thougnts as they decided whether they wished to involve their child and themselves in the Infant Project.

It was the parents' right to express these concerns and the Project's obligation to answer them openly and honestly.

Appendix A:
Selection, Admission, Follow-up after Leaving

DEVELOPMENTALLY DELAYED INFANT EDUCATION PROJECT
CRITERIA FOR INFANT SELECTION

Entrance to Program

Normal (2 in each session)

1. between 12-18 months chronological age upon entrance into program
2. scores less than one standard deviation below the normal for his/her age on the Bayley Scales of Infant Development
3. lives in Columbus' near northside and/or O.S.U. catchment area

Delayed (4 in each session)

1. under 24 months chronological age upon entrance into program
2. scores within 2nd standard deviation on the Bayley
3. lives in Columbus' near northside and/or O.S.U. catchment area

More Delayed (2 in each session)

1. under 24 months chronological age upon entrance into program
2. scores within 3rd standard deviation on the Bayley
3. lives in Columbus' near northside and/or O.S.U. catchment area.

Completion of Program

Normal

A child functioning normally upon entrance into the program has completed the program when he/she has been there for 1 year.

Delayed and More Delayed

A delayed or more delayed child has completed the program when:

1. he/she has reached a functioning level normal for his/her chronological age
2. he/she is 36 months of age chronologically

DEVELOPMENTALLY DELAYED INFANT EDUCATION PROJECT
GENERAL ADMISSION PROCEDURES

1. Initial contact (by telephone) with referral source and/or parents of referred child.
   A. fill out initial referral form (1 page).
   B. determine through discussion with parent indications of delay
   C. make appointment for testing child in home.

2. Testing of child in home.
   A. administer Denver Developmental Screening Test if no significant delay is previously indicated.
   B. administer Bayley Scales of Infant Development if 1) initial contact with parent (or referral source) indicates significant delay or 2) Denver results indicate significant delay.

3. Discussion of test results and child's general situation with executive staff of Infant Education Project.
   A. acceptance of child into project.
   B. referral of child to other community resource

4. Telephone contact with parents to inform them of test results and decision of executive staff.
   A. in acceptance cases, discuss decision with parents and set date to go over parent information packet and finalize child's entrance into program.
   B. in cases of non-acceptance, discuss decision with parents and indicate alternative resources. Contact selected alternative resource.

5. Share with other components of project plans for new child's entrance into program and make any necessary adjustments in time schedule, etc.
   A. assignment of family worker by family coordinator.

6. Home visit with parents.
   A. have family worker go along to meet family.
   B. discuss materials in parent information packet.
   C. have parents fill out and sign various forms.
   D. finalize date for child's entrance into program and responsibilities of parents.

7. Child enters program.
   A. mother (or father) attends class first two days with child; one day a week after that.
   B. check to see all necessary forms are completed, family worker has been assigned and met family, and that family has no unanswered questions.

8. Evaluation form of intake process given to parents (by mail or family worker) one week after child enters Infant Project.

FORM A **INITIAL REFERRAL** Date _____

INFO BY _____

INFORMANT _____

NAME _____ BD _____ SEX _____

ADDRESS _____
(number) (street) (city) (state) (zip)

PHONE _____ NUMBER OF PEOPLE IN HOUSEHOLD _____

FATHER _____ MOTHER _____

ADDRESS (if different from above) _____

FATHER'S EMPLOYER _____ OCCUPATION _____

MOTHER'S EMPLOYER _____ OCCUPATION _____

EDUCATION OF FATHER _____ EDUCATION OF MOTHER _____

MARITAL STATUS OF PARENTS _____

SIBLINGS: *Last Name* *First Name* *Middle Name* *BD* *Sex*

1. _____
2. _____
3. _____
4. _____
5. _____

REFERRED BY _____
(name) (address) (phone)

HOW DID YOU LEARN ABOUT THE PROGRAM?

WHAT IS THE PRESENT PROBLEM?

IN WHAT WAY CAN WE BE OF HELP?

WHAT OTHER AGENCIES ARE PRESENTLY WORKING WITH YOU?

DO YOU OWN A CAR? Yes___ No___

CAN YOU PROVIDE TRANSPORTATION FOR YOUR CHILD?

Yes___ No___

OSU D.D.I.E.P.
A. Furlong 5-72

FORM B **FOLLOW-UP REFERRAL** DATE_____

INFO BY_____

INFORMANT_____

NAME:_____PHONE_____

HOSPITAL BORN:_____BIRTH ORDER: _____ (pregnancy no.)

PLACE_____

PREVIOUS DEATHS OR MISCARRIAGES:_____

OBSTETRICIAN:_____PEDIATRICIAN_____

WHO TAKES CARE OF THE CHILD?_____

WHAT IS THE BEST AND WORST TIMES OF DAY FOR THE CHILD? _____

DESCRIBE A ROUTINE DAY FOR THE CHILD:_____

ARE THERE ANY CONCERNS FOR SIBLINGS?

EMERGENCY INFORMATION:

PHYSICIAN:_____PHONE_____

EMERGENCY PERSON TO CONTACT:_____PHONE_____

_____ DENVER SCORE: _____ _____
(date tested) (mental) (motor)

_____ BAYLEY SCORE: _____ _____ _____
(date tested) (mental) (motor) (social)

The Ohio State University
The Nisonger Center
Developmentally Delayed Infant Ed. Project

GUIDELINES
FOR
FOLLOW-UP OF CHILDREN LEAVING THE PROGRAM

Parent workers have a responsibility to develop a plan individualized for each family to provide follow-up for each child when he/she stops participating in the Infant Center. The following guideline is intended to assist parent workers in developing and implementing a plan. If a parent worker leaves the program, steps will be taken to provide coordination and follow through with a new parent worker.

A. *Alternative Programs:*

Some parents are likely to feel that their child could continue to profit from some type of program. The following are some alternatives:

1. Private Day-Care i.e. Little Darlings
   Singer
2. Public Day-Care i.e. University Day-Care
   CAMACO Day-Care Centers

   LIST OF DAY-CARE and PRESCHOOL programs to be distributed.
3. Training Programs i.e. Franklin County Program for the Mentally Retarded; ADD Program; Early Training Classes; Tom Shield—Dept. of Special Education.

B. Home Visits: During the month following termination of the child's participation in Infant Center, the family worker will continue to make weekly home visits. A minimum of one monthly home visit will be made by the family worker for at least the next five months after the child leaves the program. The purpose of these visits will be to train parents in providing stimulation for their child, and assist the family in meeting their needs.

C. *Follow-Up Evaluation:*

Annual evaluations through the first grade. This will consist of a parental interview and testing of the child.

D. A record will be maintained in the clinic chart indicating what the plan is for the family and who is responsible for implementing it.

LHI/aw
DDIEP
4/27/73

PHYSICAL EXAMINATION GUIDELINE FOR CHILD ENTERING DAY-CARE CENTER REQUIRED NOT MORE THAN THIRTY DAYS PRIOR TO ADMISSION AND ANNUALLY THEREAFTER

_____

_____
(Name of Facility)

TO BE COMPLETED BY PHYSICIAN:

I have examined _____ _____
(name of child) (age)

this _____ and certify that the child is free from
(date)

communicable disease, including tuberculosis, and is in good health. Participation in the above program will not endanger his health. He has had the following immunizations:

(Must be Completed)	Date of Series	Date of Most Recent Booster
DPT (Series of 3)		
DP (Series of 2)		
Polio		
Rubeola		Rubella
Smallpox Vaccination	Year	Scar
TB Skin Test	Year	Results

Is there any defect of hearing or vision or speech or other physical condition which would limit participation?

_____

_____

Is this child subject to any condition (such as fainting, diabetes, allergies, etc.,) which should be watched for?

_____

_____

Physician's Signature _____

Address _____

CONSENT FORM

I consent to allow my child _____ to participate in the Developmentally Delayed Infant Education Project located at Nisonger Center.

I also reserve the right to withdraw my child from the program if the need arises.

_____
Parents' signature

_____
Date

INITIAL DIETARY INFORMATION

In order that we might make your child's adjustment to and acceptance of his or her daily experience with our Infant Education Project as easy and pleasant as possible, we would like initially to provide for his lunch and snack those foods to which he is most accustomed and likes best. We also want to feed your child an appropriate amount of food, since an overfed or underfed child is not necessarily a happy child. Babies, as well as adults, are individuals in these respects, so YOU must tell US WHAT and HOW MUCH YOUR baby usually eats. Answering the following questions will help us to know these things.

When does your baby usually eat the noontime meal? _____

Does he/she have a morning/afternoon snack? _____

What time is this usually taken? _____

TYPES AND AMOUNTS OF FOODS EATEN (Circle choice or give short answer.)

MILK

Whole homo
2%
Skim
Sweetener added
Formula (type _____)

Bottle (How often?)

Cup

Amount with
Meal _____
Snack _____

How much milk (total) in one day? _____

OTHER FLUIDS	*Kinds*	*Amounts*	*How often?*
Fruit juices			
Kool Aid			
Soft drinks			
Water			

CEREAL	*Kinds preferred*	*How mixed (How much cereal–milk-water)*

FRUITS	*Kinds preferred*	Strained Junior Toddler Table	*How much / meal?*	Warmed Cold

VEGETABLES	*Kinds Preferred*	Strained	*How much per meal?*	Warmed
	_____	Junior		
	_____	Toddler	_____	Cold
	_____	Table		
	_____		_____	

MEATS	*Kinds Preferred*	Strained	*How much per meal?*	Warmed
	_____	Junior	_____	
	_____	Toddler		Cold
	_____	Baby		
	_____			

Mixed Dishes	*Kinds Preferred*	Strained	*How much per meal?*	Warmed
	_____	Junior		
	_____	Toddler	_____	Cold
	_____	Table		
	_____		_____	

Finger Foods (crackers, teething cookies, banana, hot dogs.) _____
_____

Any other foods that your child likes? _____
_____
_____

What would a typical noon meal consist of? (Kinds of foods.) _____
_____
_____

Does the baby hold his own cup? _____
Does the baby feed self with spoon? _____
Are there any foods which seem to disagree with your child or cause a rash?
_____

Is the child FAT THIN AVERAGE

Appendix B: Casefinding Information, Publicity

Most of you are familiar with the publicity campaign which took place last fall for the Infant Education Project. This involved contacting pediatricians, distributing information flyers to local residents and several newspaper articles. Although this initial effort brought us the six children and their families who are presently participating in the program, it also indicated that finding the children who can benefit from the program is not an easy task, and that a more efficient system of locating them is needed. We are presently working on what we feel is an improved plan for finding slowly developing children up to two years of age.

We are hopeful of locating these children for several reasons. The Infant Education Program is a pilot project which, it is hoped, will be replicated by other child care facilities. The longer our program continues, and expands, the more information we will have to offer those who seek to set up a similar program. Secondly, we have proposed the expansion of our present program in our facilities to include sixteen children by next fall, and the incorporation of like units in two Columbus community day-care centers. Including the children in these two Satellite Centers, the total enrollment in the Infant Education Project would be forty children.

Last, but not least, in order to assure continued funding, the need for the service the project provides must be evident. We feel the need definitely exists in the Columbus community.

Presently, we have outlined the following plan for locating children for the program:

1. to acquire two studies which may have information we can use
   A. Day Care Study—Dan Burdekin—OSU Urban Extension Program
   B. 4C Study—Coordinated Community Child Care Task Force—Pauline Mitchell, Coordinator, Columbus Technical Institute
2. contact United Community Council re: Census Tract Data (categorized by age);
3. contact Bureau of Vital Statistics re: information on children born, where located, etc.;
4. identify and contact community agencies in metropolitan Columbus who work with infants (up to 24 months) or who have extensive contact with areas of infant care:
   A. send each agency a letter of information about the infant education program
   B. follow up letter with personal phone call.

Your opinion of this plan, and any additional ideas, names of studies, agencies are invited.

JAN MORRISON/aw
4-10-72

CASEFINDING POSITION **DDIEP/The Nisonger Center/OSU**

Tentative List of Individual Contacts to be Made:

1. Mr. Bill White—Director, Family and Children's Bureau
2. Miss Beulah Wingo—Adoption and Unwed Mother's Program, The Methodist Children's Home
3. Mr. Al Hadley—Franklin County Children's Services re: Adoptive and Infant Services
4. Mrs. Mary Lee Peck—Director, Columbus Children's College
5. Dr. Ellen Hock—High-Risk Infant Program, Ohio State University Hospital
6. Well-Baby Clinic
7. Mrs. Dorothy Royce—Director, Public Health Nurses
8. Lauren Clapham O—State Welfare Department
   re: Licensed day-care homes
9. Home Trainees—Franklin County Welfare Department
10. Family Care Homes
11. Mr. Bill Lindsay—Head Start Policy Council, Parent Volunteer Coordinator.

JAN MORRISON/aw
4-10-72

March 26, 1973

Dear:

I am writing to inform you of a program in the Columbus Near Northside area to serve infants, 6 to 24 months of age with delayed development. Developmental delays in gross motor, fine motor, language and cognitive development are being treated. It is possible that you may have heard of the Developmentally Delayed Infant Education Project under the Direction of Dr. Ann S. Bardwell. We are housed at the Nisonger Center for Mental Retardation in The Ohio State University medical complex. The Infant Center has been in operation since October, 1971. Enclosed, is a brochure which gives a general description of the project. For your information I am enclosing a copy of the criteria for admission and our general admission procedures.

Additionally, I would like to enlist your support in helping to identify children who might benefit from our program, particularly those in the near northside area. There is no charge for a child's participation. Since transportation is provided, participation is generally limited to this geographical area. Presently, there are openings in the classroom in both the morning and afternoon sessions and we can take children as young as six months.

New programs such as ours often arouse questions and I urge you to contact me with any questions you have about the Infant Education Project. I would welcome your visiting the Project and observing the classroom process. I can be reached at 422-9921 from 10:00 a.m. until 2:00 p.m., Monday through Friday. Please leave a message if I am not readily available. I look forward to hearing from you soon.

Sincerely yours,

Mrs. Jacqueline A. Morrison, M.S.W., A.C.S.W.
Casefinding Coordinator
Developmentally Delayed Infant Education Project

Enclosures:

JAM/rac

36

YOU and YOUR CHILD

A FREE LEARNING EXPERIENCE FOR SELECTED BABIES 12-24 mos. OF AGE GROWING AND LEARNING ACTIVITIES

* A PROGRAM FOR INFANTS DEVELOPING SLOWLY
* FEDERALLY FUNDED THRU NISONGER CENTER—O.S.U.
* FREE SCREENING ON MONDAY-SEPT. 27, 1971*1-8:00 p.m.
* BRING INFANTS TO:
  GOOD FAITH BAPTIST CHURCH
  THIRD AVE. METHODIST CHURCH
  UNION GROVE BAPTIST CHURCH or
  MAYNARD AVE. BAPTIST CHURCH

37

TENTATIVE PLAN AND TIME LINE FOR THE INFANT EDUCATION MASS SCREENING OF INFANTS AND TODDLERS IN THE NEW NORTHSIDE CATCHMENT AREA

* * * * * *

The information gathered in the casefinding for the Infant Education Project indicates that the most lucrative system for referrals of potential candidates for the project was the mass screening done by the project staff in the fall of 1971. No other single effort has yielded such a high number of referrals. Since then, the staff commitments and needs of the expanding program have negated another such effort. However, more recently, it has been felt that another mass screening is needed, and that it would be possible to do it with the Infant Staff along with people from other programs helping with the actual testing of children with the Denver Developmental Screening Test.

Since transportation to and from the classroom can be provided only within the near northside catchment area, the focus of the mass screening and prior publicity will be in the area bounded by the Olentangy River (west), the railroad tracks just east of Cleveland Avenue (east), Hudson Street (north), and Goodale Street (south). The proposed dates for the screening are Tuesday, April 2, 1974, and Thursday, April 4, 1974, which are during the Week of the Young Child. Advance publicity would let parents know the place and hours of testing so they could bring their children between 6 months and 2 years for screening without prior appointment. Tentatively, the test administrators will be from the Infant Project, the Home Training Consultant Project, and the Competency Based Model Program. Students from other disciplines at Nisonger Center will be given the opportunity to participate.

Advance publicity will take several forms. Enlistment of support and involvement from the various service agencies, schools and churches in the defined geographical area is important to the success of the mass screening and a list of them will be ready on Monday, February 4, 1974. The staff would like to send to every agency in the catchment area a form letter briefly describing the Infant Program and the mass screening by Friday, February 8, 1974. The letter will include an invitation to a meeting of agency, school and church representatives to further discuss the mass screening on Tuesday, March 5, 1974, at 10:30 a.m. (tentative) at the Nisonger Center. The decision of where to do the screening and any changes in the dates and hours will be decided at this meeting. During the week following the mailing from the Infant Education staff the staff will call everyone on the mailing list to further enlist their interest and support and to answer questions they may have. At the meeting, community volunteers will be solicited for participation at screening sites, to distribute flyers, etc.

In addition, single page flyers about the mass screening will be posted in the area two weeks prior to the testing. It is hoped that these flyers or a letter may also be sent home with the school children and distributed at local churches at the same time the flyers are posted in community locations.

Two weeks before the screening, the places where the testing will be done will be visited to make arrangements for rooms for interviewing and testing. A list of test administrators, as well as volunteers, will be completed by mid-February and tentatively assigned to dates and hours for the screening. They will be contacted again two weeks before the screening to finalize assignment and transportation plans to screening sites.

The Denver Developmental Screening Test will be the screening instrument used. This test was found to be a near 100% effective instrument for identifying the children initially admitted to the DDIEP. There are a sufficient number of Denver kits available from the Nisonger Center faculty and staff.

ASSUMPTIONS:

The DDIEP Staff will—

1. Follow proper procedure for contacting Columbus Public Board of Education for permission to involve the school prior to sending letters to school principals.
2. Follow recommended procedure (in Center) for making intent known to and involvement of, to whatever degree the Executive Team deems appropriate, the Nisonger Center staff and students (other then those involved in the Home Economics Component).

May 8, 1974

Dear _____ :

Your child _____ was recently tested at _____ by the Infant Project—Nisonger Center—O.S.U. The results of the Denver Development Screening Test given to _____ show _____ to be functioning at this time within the normal range for _____ age.

We appreciate your bringing _____ to the screening. The Infant Project hopes to establish community screenings for young children on a 6 month basis so look for our flyers again in a few months if you wish follow-up testing for your child.

If you have any questions about the screening, or the Infant Project, I can be reached at 422-9920. Thank you for your participation.

Sincerely,

Jacqueline A. Morrison, M.S.W.
Casefinding Coordinator
Infant Education Project
Nisonger Center

JAM/mtd

40

Appendix C: *Parent Information*

DEVELOPMENTALLY DELAYED INFANT EDUCATION PROJECT

Check List of Information for Parents

I. Purpose of the Program
   A. Help parents develop a better understanding of their child and his developmental patterns
   B. Teach parents activities to use with their child in the home
   C. Provide stimulation activities for infants and toddlers in a classroom setting
   D. Conduct a comprehensive diagnostic evaluation of the child
   E. Prepare materials to train others
      1. other parents
      2. professionals
      3. students

II. Testing
   A. Denver Developmental Screening Test
   B. Bayley Scales of Infant Development
      1. given every 6 months during child's stay in program

III. Services Provided for Infant
   A. Daily 2-½ hour program
   B. Comprehensive diagnostic evaluation
   C. Free noon meal and snack
   D. Free transportation to and from Center if child lives in transportation area

IV. Parental Involvement
   A. Weekly home visits
      1. identify needs of child
      2. teach infant stimulation activities
      3. help parents meet family and personal needs that may interfere with parent-child activities, i.e., unemployment, discipline of children, strains in husband/wife relationship, medical needs
   B. Weekly visits to infant classrooms to learn infant stimulation techniques
   C. Participate in weekly parent meetings with other parents

V. Other Considerations of Interest to Parents
   A. Students are trained in the program
   B. Significant number of visitors
   C. Video-tapes and other materials will be made to demonstrate program

Jan Morrison
DDIEP, Revised 6-19-74

DEVELOPMENTALLY DELAYED INFANT EDUCATION PROJECT
PARENT PACKET CHECK LIST

A complete parent packet should include the following:	*Completed*
1. Flyer describing program	_____
2. Checklist of information for parents	_____
3. Video tape release form (2 copies)	_____
4. Dietary Information form	_____
5. Consent form (2 copies)	_____
6. Parent-Project Contact Sheet	_____
7. Physical examination form (with attached immunization schedule)	_____
8. Emergency Medical Release form (2 copies)	_____
9. Aspirin release form (2 copies)	_____

The use of the above on the home visit should be as follows (numbers correspond to numbered items above).

1. Leave with parents
2. Have parents read and leave with them
3. Leave second signed copy with parents
4. Leave with parents to fill out and bring in on child's first day in class
5. Leave second signed copy with parents
6. Leave with parents
7. Leave with parents to have doctor fill out and return to Infant Project within 30 days
8. Leave second signed copy with parents
9. Leave second signed copy with parents

Use "Completed" column to keep track of transaction on each item. Please be sure you have all of the above for your parent visit to save the family and yourself extra time and effort.

Thank you,

Jan Morrison, A.C.S.W.
Casefinding Coordinator
D.D.I.E.P.

October 8, 1971

Dear

Thank you for participating in our recent infant testing. As you know, the babies we are looking for are babies who are delayed in their development. Through an early educational experience we are confident that these infants can make significant progress in their development.

The short test which was administered to your baby can only give a rough measure of his development, therefore, our results are only an indication, not a complete diagnosis. From the results of this examination we feel your baby is developing normally and does not qualify for our program. However, if we have future programs that we think may be of interest to you, we will inform you of them.

By continuing to spend time with your child in all types of play, I am sure you will provide the many experiences necessary for his future development.

Again, on behalf of our staff, I want to express my appreciation for your cooperation.

Sincerely yours,

Loyd H. Inglis, Ed.D.
Asst. Director
Infant Stimulation Project

LHI/aw

A publication of the Developmentally Delayed Infant Education Outreach Project of the Nisonger Center for Mental Retardation and Developmental Disabilities, the Ohio State University, 1580 Cannon Dr., Columbus, Ohio 43210.

The work presented herein was performed pursuant to a grant from the Bureau of Education for the Handicapped, Office of Education, U.S. Department of Health, Education, and Welfare, Grant Number OEG 0-73-5583.

BROCHURE DESIGN: Ron Harman
The Dept. of Medical Illustration
The Ohio State University Hospitals